Accessibility and Usability in Health Information Technology (HIT):

A Research & Action Conference to Empower People with Disabilities, Older Adults, and Caregivers

Sponsored by the
Interagency Committee on Disability Research (ICDR)
Interagency Committee on Assistive Technology (ICAT)

September 17-18, 2015

U.S. Department of Education
Potomac Center Plaza, 10th Floor Auditorium
550 12th Street SW, Washington, DC 20202

Background:

The United States is moving rapidly to develop and implement smart, interconnected, health information technology (HIT) ecosystems geared to improving both the quality of care and the health of the Nation as well as to reducing costs. With the creation of health information technologies, such as electronic and personal health records (EHRs/PHRs), mobile and telehealth technology, cloud-based services, medical devices, remote monitoring devices, assistive technologies, and the underlying infrastructure that enables the exchange, consumers and health care providers can access and use HIT systems and tools to inform decision-making, support coordinated health management, and to engage as partners to improve health outcomes. However, to deliver on the "promise" of HIT for all Americans, including persons with disabilities, older adults and caregivers, electronic health information must be both accessible and usable for providers and consumers alike. Having accurate and accessible health information available when, where, and how it is needed is also pivotal for supporting the new person-centered health paradigm. This state of the science conference is devoted to advancing the accessible HIT agenda. Facilitated discussions among diverse stakeholder groups will identify gaps and barriers, and propose actionable solutions that will promote a shared culture of inclusion and person-centered care.

Purpose:

To advance the priority of accessibility in HIT systems and tools from a compliance-oriented approach toward one that is user-driven, responsive to human-centered consumer experiences, and results in increased patient engagement and improved health and wellness for individual disabilities, older adults, and caregivers.

Who Should Attend?

Disability, aging, accessibility, and HIT researchers and developers, policymakers, government and industry representatives, aging and disability advocates, providers, people with disabilities, older adults and caregivers. Seating is limited so please register early and plan to participate in the entire conference.

Objectives:

- To elevate the importance of accessibility and usability in the nation's HIT agenda to better meet the needs of individuals with disabilities, older adults, caregivers, and providers.

- To exchange perspectives among diverse stakeholder groups and identify barriers and potential levers of change for creating an accessible HIT ecosystem.
- To highlight the latest research findings and identify best practices and actionable strategies that advance knowledge about health care methods, models, and tools associated with accessible, interoperable and person-centered health IT systems.
- To catalyze new research and development initiatives and collaborative partnerships that move the accessible HIT agenda forward to achieving the Triple Aim of improved patient care, reduced costs, and improved health outcomes for individuals with disabilities, older adults and caregivers.

Conference Products:
- Archived Presentations
- Conference Proceedings
- Journal Publication Submission

Draft Agenda

September 17, 2015 – Exchanging Perspectives, Identifying Barriers and Facilitators

8:00 a.m. – 8:30 a.m.   **Registration, Coffee, and Networking**

8:30 a.m. – 8:50 a.m.   **Welcome and Opening Remarks**

Co-Chair's Welcome & Introductions
Margaret Campbell, PhD
Senior Scientist for Planning and Policy Support
National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
Administration for Community Living (ACL)
U. S. Department of Health and Human Services

Kathy McCoy, PhD
National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
Administration for Community Living (ACL)
U. S. Department of Health and Human Services

Samantha Meklir
Director, Division of Strategic Policy
Office of the National Coordinator for Health
IT Office of Policy
U.S. Department of Health and Human Services

Opening Remarks
John Tschida
Chair, Interagency Committee on Disability Research (ICDR)
Director, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
Administration for Community Living (ACL)

U. S. Department of Health and Human Services

Sharon Lewis
Principal Deputy Administrator
Administration for Community Living (ACL)
U. S. Department of Health and Human Services

8:50 a.m. – 9:15 a.m. **Keynote Speaker – Elevating Accessibility and Usability in the Health IT Agenda to Better Meet the Needs of Older Adults, People with Disabilities and Caregivers**

Frank Baitman
Chief Information Officer
U. S. Department of Health and Human Services

Moderator: *Deborah Kaplan, CIO/HHS*

9:15 a.m. – 9:30 a.m. **Moderator Facilitated Q&A**

9:30 a.m. – 10:35 a.m. **Panel 1: Voices and Perspectives of End Users – Needs, Barriers and Opportunities Associated with Using HIT Systems and Tools**

MaryAnn Sterling
Co-Founder
Connected Health Resources

John G. Paré, Jr.
Executive Director for Advocacy and Policy
National Federation of the Blind

Jeromie Ballreich
Consumer, PhD Student, Health Economics
John Hopkins University

Carol Bradley
Disability Compliance Officer
Sutter Health

Chanel Lakey
Web Developer
Sutter Health

Gail Hunt
President and Chief Executive Officer
National Alliance for Caregiving

Moderator: *Karl Cooper, American Association on Health and Disability*

10:35 a.m. – 10:50 a.m. **Moderator Facilitated Q&A**

10:50 a.m. – 11:05 a.m.	**Break**
11:10 a.m. – 11:40 a.m.	**Small Group Huddle**
11:40 a.m. – 12:40 p.m.	**Lunch (purchase your lunch and bring it back to the room for the next panel)**
12:40 p.m. – 1:40 p.m.	**Working Lunch -** **Panel 2: Building Blocks for Accessible and Usable HIT: Overview of Current Landscape-What Standards and Tools Exist and Where are the Gaps (including EHR & PHR?)** *Judy Brewer* *Director, Web Accessibility Initiative* *World Wide Web Consortium* *Muhammad F. Walji, PhD* *Associate Director and Project Leader* *National Center for Cognitive Informatics and Decision Making in Health Care* *ONC SHARP Program* *SHARP Project* *Janey Barnes, PhD* *Human Factors Specialist* *User-View, Inc.* *Caitlin Blood* *Healthy People Communication Fellow* *Office of Disease Prevention and Health Promotion* *U.S. Department of Health and Human Services* **Moderator**: *David Baquis, U.S. Access Board*
1:40 p.m. – 1:55 p.m.	**Moderator Facilitated Q&A**
1:55 p.m. – 2:10 p.m.	**Break**
2:10 p.m. – 3:15 p.m.	**Panel 3: Federal Policy Perspectives: Incorporating Accessibility and Usability into HIT and Electronic Long-Term Services and Supports (eLTSS) Systems and Initiatives – Barriers and Levers of Change** *Amanda Maisels, JD* *Deputy Chief, Disability Rights* *U.S. Department of Justice* *Raja S. Kushalnagar, JD, LLM, PhD* *Assistant Professor* *Information and Computing* *National Technical Institute for the Deaf*

Jodi G. Daniel, JD, MPH
Director, Office of Policy
Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services

Michael Smith
Director, Division of Community Systems Transformation
Centers for Medicare and Medicaid Services (CMS)

Caroline Ryan
Administration for Community Living, (ACL)
Center for Disability and Aging Policy
U.S. Department of Health and Human Services

Moderator: *Samantha Meklir/ONC*

3:15 p.m. – 3:30 p.m.   **Moderator Facilitated Q&A**

3:30 p.m. – 4:10 p.m.   **Small Group Huddle**

4:10 p.m. – 4:50 p.m.   **Wrap-up Conversation Among Key Stakeholders – Identifying Innovative Strategies for Overcoming Accessibility and Policy Barriers**

Judy Brewer
Director, Web Accessibility Initiative
World Wide Web Consortium

Gail Hunt
President and Chief Executive Officer
National Alliance for Caregiving

Jodi G. Daniel, JD, MPH
Director, Office of Policy
Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services

Moderator: *Matthew Quinn, Intel*

4:50 p.m. – 5:00 p.m.   **Charge for Day 2 and Adjourn**

Margaret Campbell, PhD
National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)

September 18, 2015 – Advancing Research and Development, Identifying Best Practices, Building Collaborative Public-Private Partnerships

8:00 a.m. – 8:30 a.m.	**Registration, Coffee and Networking, and Order Lunch**

8:30 a.m. – 8:50 a.m.   **Welcome and Opening Remarks**

Welcome
Kathy McCoy, PhD
National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
Administration for Community Living (ACL)
U. S. Department of Health and Human Services

Opening Remarks
Tiffani Bright, PhD
Senior Service Fellow
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality (AHRQ)
U.S. Department of Health and Human Services

Wendy Nilsen, PhD
Program Director
Smart and Connected Health Program
National Science Foundation

8:50 a.m. – 9:15 a.m.   **Keynote Speaker – Incentivizing Research and Building Collaborative Partnerships and Inclusive Platforms – Moving the Accessible HIT Agenda Forward to Better Serve Diverse Populations**

Frances W. West
Chief Accessibility Officer
IBM

Moderator: *TBD*

9:15 a.m. – 9:25 a.m.   **Moderator Facilitated Q&A**

9:30 a.m. – 10:45 a.m.   **Panel 4: R&D Perspectives – What We Know and Need to Know to Drive Accessible HIT Policy and Practice – Metrics, Data, and Best Practices?**

Bambang Parmanto, PhD
Professor
Health Information Management and Biomedical Informatics
University of Pittsburgh

Dean Karavite
Lead Human Computer Interaction Specialist

Department of Biomedical and Health Informatics (DBHi)

Madeleine Rothberg
Senior Subject Matter Expert
National Center for Accessible Media at WGBH

David Gustafson, PhD
Professor, Industrial Engineering and Preventive Medicine
University of Wisconsin in Madison

James (Jim) Rimmer, PhD
Director
Lakeshore Foundation/University of Alabama-Birmingham Research Collaborative
University of Alabama at Birmingham

Moderator: *Tiffani Bright/AHRQ*

10:45 a.m. – 11:00 a.m.	**Moderator Facilitated Q&A**
11:00 a.m. – 11:15 a.m.	**Break**
11:15 a.m. – 11:45 a.m.	**Small Group Huddle**
11:45 a.m. – 12:45 p.m.	**Lunch (purchase your lunch and bring it back to the room for the next panel)**

12:45 p.m. – 1:40 p.m.   **Working Lunch d**
Panel 5: Industry and Advocacy Perspectives - Next Steps in Creating an Accessible HIT Ecosystem

Mark Richert, Esq.
Director, Public Policy
American Foundation for the Blind

Elaine A. Blechman, PhD
President, Prosocial Applications, Inc.
Professor Emerita, University of Colorado at Boulder

David Lindeman, PhD
Director
Center for Technology and Aging

Kel Smith
Principal
Anikto, LLC

Moderator: *Robert Jarrin/Qualcomm*

1:40 p.m. – 1:55 p.m.   **Moderator Facilitated Q&A**

1:55 p.m. – 2:25 p.m.   **Wrap-Up Conversation– Identifying Innovative Strategies to Promote R&D Investments and Collaborative Public-Private Partnerships that Catalyze Action to Advance Accessible HIT**

David Lindeman, PhD
Director
Center for Technology and Aging

Frances W. West
Chief Accessibility Officer
IBM

William Peterson
Executive Director, Office of Accessible Systems and Technology
U.S. Department of Homeland Security
Moderator: Margaret Campbell, NIDILRR

2:25 p.m. – 2:30 p.m.   **Next Steps and Adjourn**
Kristi Wilson Hill, PhD
ICDR Interim Executive Director
Deputy Director, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
Administration for Community Living
U.S. Department of Health and Human Services